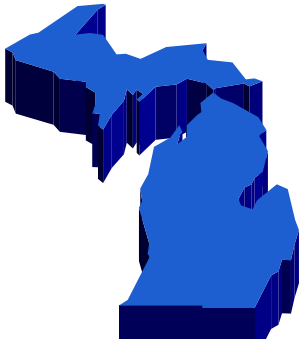


# *The Michigan FAS Web*



*"When spider webs unite they can tie up a lion."  
~African Proverb~*

## **The University of Michigan FAS Clinic: Diagnostic and Intervention Services**

The first FAS diagnostic clinic in Michigan began providing services in 1996 as a result of two individuals fortuitously meeting at a conference and discovering a shared vision. Dr. Sheila Gahagan, developmental/behavioral pediatrician and research scientist at The University of Michigan was presenting at the conference. She described her long-standing interest in FAS and her work with families affected by FAS in Arizona between 1984 and 1995. Barb Wybrecht, long-time advocate for individuals affected by prenatal exposure to alcohol, approached Dr. Gahagan to share her own work and interest in FAS. The University of Michigan's Diagnostic Clinic for Fetal Alcohol Syndrome was the result of the collaboration of these two committed individuals.

Clinics were originally scheduled on a bimonthly basis, with 4 clients typically seen at each clinic. Thanks to a state of Michigan training grant in 1999, ten staff and volunteers were able to travel to

Seattle to participate in training at the University of Washington with Dr. Sterling Clarren.

A generous gift to the UM clinic from the Speckhard-Knight foundation in the fall of 2001 has enabled the clinic to significantly increase the number of children served. Instead of bimonthly clinics, the UM FAS Clinic now provides diagnostic clinics twice a month. In addition, intervention services are now offered to affected children and their families. These services are provided by a psychologist, an occupational therapist, a nurse practitioner, parents who have raised a child with FAS, and pediatricians. These services include working with families to better understand their child's diagnosis and helping them obtain needed school and/or community services for their child.

For more information contact the Clinic at [mlheys@umich.edu](mailto:mlheys@umich.edu) or 734/663-4241.

### **~NEW RESEARCH RESOURCE~**

The National Institute on Alcohol Abuse and Alcoholism's journal, "**Alcohol Research and Health**," devoted its entire third issue in 2001 to an update on Alcohol-Related Birth Defects. Articles include:

- The prevalence of Fetal Alcohol Syndrome
- Teratogenic effects of alcohol on brain and behavior
- Fetal alcohol exposure and attention
- Alcohol screening instruments for pregnant women
- Markers to detect drinking during pregnancy
- Alcohol's effect on lactation

Free copies of these journal articles can be accessed online at <http://www.niaaa.nih.gov/publications/aharw.htm> or a copy of the full journal can be purchased for \$9.00 through the Government Printing Office, call (202) 512-1800.

## Screening for FAS: A Community Approach - - That Works!!



The Lac Vieux Desert Behavioral Health Program has had tremendous success in helping families in the Upper Peninsula through the FAS screening and diagnostic process. Their impressive accomplishments and extraordinary efforts were recently featured at the Inter-Tribal Healthy Start quarterly meeting in Sault Ste. Marie.

We hope this information will also serve as a guide or inspiration to communities who may be struggling with their own screening efforts. The Lac Vieux Desert Behavioral Health Program views the key to their success as having the screening process interwoven within their multifaceted community response to working on FAS. The effort involves education, barrier removal, community role models and collaboration.

### **EDUCATION:**

In the early phases of this work, extensive staff and community education and awareness building was necessary. Many different trainings were held for teachers, service providers, Tribal department heads and community members. Ongoing education and awareness efforts continue to be a big part of the effort. Creative outlets for education have been used including distributing educational placemats to casinos, holding poster contests, and sharing information at powwows and “New World” and “Spirit” run/walks. Information is also communicated through radio ads, billboards, newsletters, health fairs, and classes for youth and teachers. As the community learns more about this issue the need for screening and diagnosis become very evident.

### **BARRIER REMOVAL:**

A very important key to helping families access diagnostic services is through eliminating or reducing stigma or other attitudinal barriers. Service providers must be willing to examine their own beliefs regarding alcoholism to avoid making the parent feel judged. When discussing the possibility of prenatal alcohol exposure it is helpful to ask a woman if she could have consumed alcohol *before she knew* she was pregnant. Parents also need to know that many children affected by prenatal exposure to alcohol look normal and can be very smart but may develop significant academic or behavior problems without an appropriate diagnosis. Another strategy for reducing stigma is through the sharing of personal stories from parents.

The Lac Vieux Desert Behavioral Health Program’s Health Director is a Tribal member and parent of twins with ADHD and FAE. She shares her personal experience and success with other parents, school administration and teachers. This is very important for establishing credibility and building trust.

### **REFERRAL SYSTEM:**

The screening process requires a strong commitment from agency directors and the dedication of many staff. The community is fortunate to have close working relationships between the primary care clinic, Behavioral Health and Healthy Start programs to allow for ease of referrals. Also as the result of the educational/awareness building efforts, requests for screening come from school, social services, Tribal and non-Tribal service providers and directly from caregivers. A team approach is used for delivering screening services. This allows for increased screener availability, shared workload, broader community contact and a choice of screener increases the chance of client comfort with the process. Assistance is also provided to help families collect the extensive information necessary for a diagnostic clinic appointment.

### **SUPPORT:**

Much work is needed to provide assistance in accessing diagnostic services and for continued support of affected individuals. The Lac Vieux Desert Behavioral Health Program’s Health Director advocates for recognition and addressing FAS at a community level. For example, she supports the avoidance of alcohol sales at family events and has encouraged parents of FAS children to run for school board elections. She also encourages tribal support of paid time off to attend counseling, IEP’s and family case conferencing. Grants are being sought to help secure case management and resources for families coping with FAS. In Lac Vieux Desert, parents are also empowered through a support group to learn about adapting to meet their child’s needs and also on how to educate professionals to do the same. While providing adequate support and follow-up services is an immense issue, it is believed to be crucial to maintaining the integrity of the community effort.

For more information on this project, contact Terry Fox at (906) 358-4589.

## Changes at the State

As many of you know, I will be retiring in late August. Actually, for me it feels like a graduation, as I will be going to California to a new career, working in direct service related to my nutrition background. At any rate, this article gives me an opportunity to make parting comments about our FAS program in Michigan.

It has been a real privilege and a pleasure to work with you all with this important FAS work. It is apparent that you all feel the same, as your enthusiasm, commitment, creativity, and charity is obvious. This is what has made our program a success. And I am happy to say that our program will continue, and probably even grow in the future.

We are fortunate to have a core funding of \$200,000 from the state for our FAS efforts which, in spite of a recent scare, looks stable for the years to come. With local financial and voluntary support, especially in the diagnostic clinics, our FAS efforts reflect about \$750,000 in Michigan. And that does not count the many efforts of those not contracted with the state's program.

During the past three years we have made available a selection of quality FAS pamphlets and educational materials, established 11 community projects, 5 FAS Diagnostic teams, a Statewide FAS Workgroup, and a group of trained presenters making FAS awareness and prevention presentations to a wide variety of local audiences. During the past year alone we have made 140 community presentations on FAS, reaching 4,233 participants! And this number includes only the data given to me via presentation records and community project reports. Finally, we have also been awarded supporting grants—and came very close to receiving a much larger one.

The community projects and diagnostic teams continue to explore ways to increase services and meet needs beyond what was expected when we entered into contracts. As just one example, the diagnostic teams are trying different ways to provide follow-up services to children and their families after their clinic visit. As many of us see it, this is the major area of unmet need. To meet this need will require extensive additional funding.

I am confident that current activities and more will continue because our program's tasks will be in excellent hands. Kathy McGarry (517-335-8976) will be handling the fiscal responsibilities. Our Statewide FAS Workgroup will do program development and coordination. Sarah Horton Bobo will take over my organization and staffing responsibilities with the group. Consultants are in place for each community project. My supervisor, Paulette Dobynes Dunbar, will be involved with policy decisions, and Jim Henry, director of the clinic in Kalamazoo will lead our group with grant writing efforts.

I want to say thanks specifically to the Statewide FAS Workgroup, which provides program direction, coordination, keeps us in-touch with the newest information, comes up with new ideas, and carries out many activities. It will continue to be important for the future of FAS in Michigan. Sarah Horton Bobo, Martie Manty, Karen Twa, Connie Black-Pond and Patricia Gushman comprise this group.

In summary, with this optimistic view of the future, I want to say a sincere thank you to all of you for all that you do!

*Bill Holland*

*"You can tell more about a person by what he says about others than you can by what others say about him."*

*Leo Aikman*

**THANK YOU BILL—WE WILL MISS YOU!**

## *The Arc Muskegon*

In October 2001, The Arc National was awarded a grant from the Centers for Disease Control and Prevention (CDC) to develop an FAS curriculum guide geared to parents and professionals. The four main components of the curriculum will be:

- FAS overview
- Adult learning strategies (what works/what doesn't)
- Coping strategies for families and professionals
- Local resources

The Arc National has worked tirelessly for the past ten years to help reduce the incidence of FAS and other alcohol related neurological disorders through education, research and awareness. Seven local and state chapters of the Arc who have also been active in the awareness and prevention of FAS were chosen to participate in the grant, including Arc/Muskegon. The task of the local and state chapters will be to gather data by holding focus groups, reporting all data collected, providing input from their own experiences, and be a pilot site for the curriculum.

Arc/Muskegon's first focus group was held in April. The Grand Rapids Fetal Alcohol Parent Support Group eagerly accepted the invitation and provided our organization with valuable firsthand knowledge about their experiences caring for children with FAS. The information from this focus group and others from around the country is being



sent to the University of Minnesota where the data will be compiled. Over the course of the three year grant, this information and other research, will be used to develop an effective and cutting edge tool through which families and professionals will forever benefit. Arc/Muskegon is thrilled to take part in this project and appreciates the regional support.

*Together it works!*

**Michigan FAS Web Newsletter**  
**c/o Kent County Health Department**  
**700 Fuller NE**  
**Grand Rapids, MI 49503**